Quality Standards

Health Quality Ontario

Let's make our health system healthier

Ontario Palliative Care Network

Patient Reference Guide

Palliative Care

Care for Adults

Quality standards outline what high-quality care looks like. They focus on topics where there are large variations in how care is delivered, or where there are gaps between the care provided in Ontario and the care people should receive.

This guide addresses variations and gaps in care in Ontario that need attention when it comes to palliative care. It is based on the best available evidence and was created in partnership with family, caregivers, and health care providers.

The quality standard, available on our website, contains more information. You can find it at hqontario.ca.

In this guide, we use the following terms:

- **Family:** The people closest to you, including your biological family, family by marriage, and friends. You define who your family is and how they will be involved in your care.
- **Caregiver:** Someone who provides unpaid care and support for you, such as family members, friends, and anyone else you identify.
- **Care team:** A group of health care providers who work together to care for you. Your care team may include doctors, nurses, social workers, volunteers, personal support workers, and spiritual care providers.
- **Substitute decision-maker:** Someone who makes care and treatment decisions for you if you are mentally incapable of making decisions for yourself.
- **Goals of care:** Your priorities and how you want to be cared for, based on your values, wishes, and beliefs.
- **Health care consent:** There are two parts to health care consent. First, you and your health care team discuss your condition, treatment options, risks and benefits, side effects, and what would happen without the proposed treatment. Once you understand those things, you decide to give or refuse permission for the treatment.

This guide is for people who are living with a progressive, life-limiting illness. It can help you to know what to ask for when receiving treatment and to make sure you receive the highest-quality care.

Palliative care is a philosophy of care that aims to relieve suffering and improve quality of life for people with a progressive, life-limiting illness, and for their families and caregivers too. Palliative care can help improve your quality of life at any stage of illness and is not just for end of life. You can also receive palliative care while you are being treated for your illness.

Progressive, life-limiting illnesses such as cancer, heart failure, chronic obstructive pulmonary disease, and dementia can affect health and quality of life and can lead to death. Anyone with such an illness can benefit from a palliative approach to care.

Living with this type of illness can be hard on you and your family and caregivers, both physically and emotionally. Palliative care helps by addressing all aspects of your well-being—physical, psychological, social, spiritual, linguistic, cultural, and practical.

This quality standard does not address medical assistance in dying. People who choose medical assistance in dying should receive high-quality palliative care.

If you or someone you care about is living with a progressive, life-limiting illness …

You can use this guide to work with your care team to make a care plan that works for you. We encourage you to use this guide to ask informed questions and to learn how you and your family and caregivers can get the supports you need.

Care plans can be very different for each person, so it is important to work closely with your care team to create a care plan that works for you.

Here are some things to consider.

Your Care Team

- You should have access to care providers who are knowledgeable about palliative care and who will work together to meet your needs and goals of care.

Understanding Palliative Care

- Your care team should give you, your family, and your caregivers information about palliative care. They should also give you information about palliative care resources and supports, such as counselling, hospice volunteers, wellness programs, spiritual care, or support groups. This knowledge can help you understand your treatment and service options, how palliative care can improve your quality of life, and how to connect with available supports.

Your Care

- Your care team should talk with you about your illness and how it could progress. They should also talk with you about your values and goals and your treatment options. These discussions will help you understand your illness, your goals of care, and your treatment options so you can make decisions about your care and provide health care consent.
- Your care team should assess what palliative care or supports you need:
  - They should ask questions about your physical and mental health, your support system, and any other needs you feel you have, to understand how best to help you
  - They should assess your pain and other health concerns, and manage them quickly and effectively
  - They should assess your mental, emotional, social, cultural, and spiritual well-being
  - They should ask your family members and caregivers about the help they need
- Your care team should work with you to create a care plan that fits your values, wishes, and goals. Your care team should use this plan to provide palliative care that meets your needs. This care plan should be updated as often as you need.
- Your care team should talk with you about where you would like to be cared for throughout your illness and at the end of life (for example, at home, in a home-like environment called a hospice residence, in a hospital, or in a long-term care home). They should give you information about the care available in different locations to help you make the best choices for you, your family, and your caregivers. Your wishes may change over time, so you should have regular opportunities to discuss them. You may want to talk about:
  - Your preferences
  - How your disease affects your ability to perform normal daily activities
  - Whether you are living with someone who can help you
  - Whether other help you may need is available
- Palliative care support should be available for you whenever you need it, day or night.

Substitute Decision-Maker

- Make sure you know who your future substitute decision-maker will be, by Ontario law, if you become incapable of making health decisions. Ontario's *Health Care Consent Act* automatically assigns a substitute decision-maker.
- If the person Ontario's *Health Care Consent Act* automatically assigns to be your substitute decision-maker is **not** the person you want in this role, prepare a legal document called a "Power of Attorney for Personal Care." It is not enough to tell your care team that you want a different substitute decision-maker.
- Once you have confirmed your substitute decision-maker, talk with them regularly about your wishes, values, and beliefs. This will help them make the right decisions for you, if needed. If your wishes change, keep them informed.
- For more information, excellent resources are available from Speak Up Ontario: www.speakupontario.ca

When You Change Care Settings or Providers

- When you change care settings or care providers (for example, if you return home after being in hospital), your care team should work with you to make sure you and any new team members have the right information (such as information about your medication). They should also make sure you receive the services you need (such as plans for follow-up).

Supporting Caregivers

- Caregiving can be a rewarding experience, but it can also be stressful. If you are a caregiver, a member of the care team should assess you to see how you are coping and help you get the supports you need. Supports can include training, support groups, home care, and temporary respite care for the person you are caring for. Respite care can give you a break from the caregiving routine and give you time to take care of yourself.

Here are some questions you can ask your health care team to help you get the highest-quality palliative care:

Who is part of my care team?

What are my treatment options?

What palliative care supports are available where I live?

Where can I get more information and support?

Who can I contact if I need to speak to someone?

What should I do in an emergency?

.....

.....

.....

.....

.....

.....

Living with a progressive, life-limiting illness can be difficult. Your care team will work with you to ensure your care addresses all aspects of your well-being and is tailored to you.

Everybody is different, and some options may not apply in your situation. If you have questions about your care, it is important to speak with your health care professional.

Looking for More Information?

Please contact us at **qualitystandards@hqontario.ca** or **1-866-623-6868** if you have any questions or feedback about this patient reference guide.

The quality standard, available on our website, contains more information. You can find it at hqontario.ca.

About Health Quality Ontario

Health Quality Ontario is the provincial advisor on the quality of health care. We are motivated by a single-minded purpose: **Better health for all Ontarians.**

Our quality standards are concise sets of statements outlining what quality care looks like for conditions or topics where there are large variations in how care is delivered, or where there are gaps between the care provided in Ontario and the care patients should receive. They are based on the best available evidence and are developed in collaboration with clinical experts from across the province, and patients and caregivers with lived experience with the topic being discussed.

For more information about Health Quality Ontario and our quality standards, visit: **hqontario.ca.**

About the Ontario Palliative Care Network

The Ontario Palliative Care Network is a partnership funded by the Ministry of Health and Long-Term Care and led by CCO, the Local Health Integration Networks, Health Quality Ontario, and the Quality Hospice Palliative Care Coalition of Ontario. It is putting patients and families at the centre of every decision and strengthening hospice palliative care services across Ontario. This work is person-centred, focused on supporting the provision of quality hospice palliative care for all Ontarians, regardless of their age or disease type. The Ontario Palliative Care Network will help to ensure that hospice palliative care in Ontario is high-quality, sustainable, accessible, continuous, and person-centred.

ISBN 978-1-4868-1412-1 (Print)
ISBN 978-1-4868-1422-0 (PDF)
© Queen's Printer for Ontario, 2018

Ontario
Health Quality Ontario